ANSWERS TO YOUR QUESTIONS ON
RETINITIS PIGMENTOSA AND OTHER
RETINAL DEGENERATIVE DISEASES.

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ANSWERS TO YOUR QUESTIONS ON RETINITIS PIGMENTOSA and other retinal degenerative diseases

RP FOUNDATION FIGHTING BLINDNESS
8331 Mindale Circle
Baltimore, Maryland 21207
1-800-638-5682 (*toll-free*)
(301) 655-1011 (*Maryland residents*)
TDD: (301) 655-1190 (*for deaf*)

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1) <u>What is Retinitis Pigmentosa (RP)?</u>

RP is the name given to a group of diseases which affect the retina of the eye. The retina, located in the back of the eye, is the part of the eye that acts like the film in a camera. It is a delicate layer of cells which picks up the picture and transmits it to the brain--where "seeing" actually occurs. In RP, the retina begins to degenerate, which causes vision to diminish.

2) <u>What are the symptoms of RP?</u>

One of the earliest symptoms of RP is difficulty seeing at night or in dimly lit places (night blindness). Later there is a reduction in side (peripheral) vision. The symptoms of RP generally increase over the years. When other members of a family are also affected, the rate of progression is usually similar within that family.

3) <u>What causes RP?</u>

It is known that certain cells in the retina known as rods and cones die in RP. The cause of cell death, however, is not known at present. But research provides us with the opportunity to seek solutions.

4) <u>Who is conducting this research?</u>

Through the efforts of the RP Foundation Fighting Blindness, the number of highly-qualified scientific investigators working full time on RP and related diseases around the country continues to grow. Research efforts in this type of retina disease are difficult because there is no opportunity to safely biopsy (remove and examine living retinal tissue under microscope) the delicate eye.

5) <u>What is an RP Research Center?</u>

The RP Foundation supports research at a number of medical centers and hospitals internationally to find the cause, prevention and treatment of retinal degenerative diseases like retinitis pigmentosa, Usher's syndrome and some forms of macular degeneration. Some of these centers also provide a clinical evaluation of the patient's

RP OR OTHER RETINAL DEGENERATION. THEY ALSO MAY PERFORM SPECIAL TESTS REQUESTED BY THE PATIENT'S OWN OPHTHALMOLOGIST. IT IS STILL IMPORTANT FOR A PATIENT WITH RP TO BE UNDER CARE OF HIS OR HER OWN EYE DOCTOR.

6) IS THERE A TREATMENT TO ARREST THE PROGRESSION OF RP?
AT PRESENT THERE IS NO TREATMENT AVAILABLE TO ARREST THE PROGRESSION OF RP, ALTHOUGH MANY UNPROVEN "TREATMENTS" HAVE BEEN ATTEMPTED. TO DATE, NO CONVINCING SCIENTIFIC EVIDENCE HAS BEEN OFFERED TO DEMONSTRATE ANY BENEFITS FOR INDIVIDUALS WITH RP FROM THESE SO-CALLED TREATMENTS. YET OUR SCIENTISTS ARE ALWAYS ON THE LOOK-OUT; EVEN THE MOST REMOTE POSSIBILITIES ARE BEING INVESTIGATED.

7) HOW DOES RP EVENTUALLY AFFECT VISION?
WHILE EACH INDIVIDUAL CASE DIFFERS, A NUMBER OF INDIVIDUALS WITH RP HAVE LIMITED VISION THROUGHOUT THEIR LIVES.

8) CAN RP CAUSE BLINDNESS?
BLINDNESS, TO THE LAYMAN, INDICATES A COMPLETE LOSS OF ALL SIGHT. HOWEVER, ALTHOUGH SOME RP PATIENTS BECOME BLIND IN THIS SENSE, MOST WILL RETAIN AT LEAST LIMITED RESIDUAL VISION TERMED "LEGAL BLINDNESS".

9) WHAT IS MEANT BY THE TERM "LEGAL BLINDNESS"?
LEGALLY BLIND INDIVIDUALS ARE THOSE WHOSE VISUAL SHARPNESS OR ACUITY (WITH GLASSES IF NEEDED) IS 20/200 OR WORSE IN THE BETTER EYE; OR WHOSE VISUAL FIELD REGARDLESS OF VISUAL ACUITY IS RESTRICTED TO A 20-DEGREE DIAMETER OR 10-DEGREE RADIUS.

10) HOW QUICKLY WILL MY VISION DIMINISH?
EACH PATIENT MUST BE INDIVIDUALLY EVALUATED BY AN EYE DOCTOR BECAUSE THE PROGRESSION OF RP IS SO VERY DIFFERENT FOR EACH INDIVIDUAL. HOWEVER, MOST RP PATIENTS HAVE A VERY GRADUAL PROGRESSION OF SYMPTOMS WHICH ALLOWS FOR AN ADJUSTMENT TO THE VISUAL HANDICAP.

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11) <u>Can RP be easily diagnosed</u>?

This depends on the type and extent of RP. Frequently, a characteristic change in the appearance of the retina is visible. In addition to a routine eye exam, other tests are sometimes required to determine the precise state of the retina.

12) <u>Is only vision affected by RP</u>?

No, sometimes it is not. Some people with RP are also born deaf. When this occurs it is called Usher's syndrome.

13) <u>What about cataracts and RP</u>?

It is not unusual for an individual with RP to develop cataracts, a haziness of the lens of the eye. In cases where cataracts significantly interfere with vision, it may be advisable to remove them surgically. Whether or not surgery helps to improve vision often depends on how far the retinal changes have advanced. Because surgery is not for everyone, it is necessary to discuss its advisability with an ophthalmologist.

14) <u>Does night blindness mean a patient has retinitis pigmentosa</u>?

It does not. Night blindness can be a symptom of a number of retinal diseases besides RP, and in some cases does not represent any significant eye disorder.

15) <u>Are there other retinal degenerations besides retinitis pigmentosa</u>?

Yes, there are many; some doctors use the term "RP" to encompass all of these degenerations.

16) <u>Can an eye transplant be performed</u>?

No. The retina (the layer of cells in the eye affected by RP) is connected to the brain and within the limits of present-day scientific knowledge cannot be transplanted. Although you may hear about eye transplants being performed, this refers to corneal transplants, which have no relationship to RP.

17) <u>What are the effects of vitamin treatments</u>?

Although good nutrition is necessary for good health, vitamin treatments, as far as our scientific advisors can ascertain, are not helpful in treating retinitis pigmentosa. There is no proven vitamin deficiency or shortage in patients with RP. Thousands affected by RP have taken large quantities of vitamins, especially Vitamin A, without beneficial effect.

18) <u>Does light have an effect on RP</u>?

There is no scientific evidence that normal light levels worsen the symptoms of RP. Individuals with RP and other retinal degenerations are encouraged to protect their eyes from long exposure to bright light as a precaution until more is learned. In dim light they may use their eyes to the degree possible without fear of worsening their condition.

19) <u>There are times when my vision seems better or worse. Does this happen to others</u>?

There are a number of factors which might account for "good days" or "bad days" for someone with RP. Some individuals feel they are able to see better on cloudy days; others feel they do not see as well. Fatigue or emotional stress may also have temporary effect on vision. All people have days when, for no apparent reason, they seem to function better or worse than others. The same is true for those affected by RP.

20) <u>Does pregnancy have an effect on RP?</u>

We do not know of any evidence that pregnancy affects retinitis pigmentosa, but the matter has not been properly studied to date.

21) <u>Is RP inherited</u>?

In most instances it is inherited. The most common inheritance of RP is called "recessive". This means that two donors of the gene are needed to acquire RP, although the individuals involved may not have RP. Such individuals are known as carriers. When two carriers marry, the chance that a given child will be affected is one out of four.

ANOTHER FORM OF RP INHERITANCE IS "SEX-LINKED". IN SEX-LINKED RP THE MOTHER IS THE CARRIER. IF A FEMALE CARRIER OF SEX-LINKED RP MARRIES A NORMAL MALE, THERE IS A 50% PROBABILITY HER SONS WILL BE AFFECTED AND A 50% CHANCE HER DAUGHTERS WILL BE CARRIERS. SEX-LINKED RP IS THE ONE FORM IN WHICH CARRIERS CAN OFTEN BE DETECTED.

THE THIRD INHERITANCE PATTERN IS CALLED "DOMINANT". IN THIS TYPE, AFFECTED PERSONS HAVE AN AFFECTED PARENT, BUT UNAFFECTED CHILDREN WILL HAVE UNAFFECTED OFFSPRING. THE RECURRENCE RISK FOR THE OFFSPRING OF AN AFFECTED PERSON IS ONE IN TWO, AND MALES AND FEMALES ARE AFFECTED IN EQUAL PROPORTIONS.

BECAUSE RP RUNS IN FAMILIES, ALL FAMILY MEMBERS ARE ENCOURAGED TO HAVE A THOROUGH EYE EXAMINATION.

22) <u>HOW CAN I DETERMINE THE LIKELIHOOD OF MY CHILDREN AND OTHER FAMILY MEMBERS BEING AFFECTED</u>?

INFORMATION AS IT RELATES TO YOUR INDIVIDUAL FAMILY SITUATION SHOULD BE ADDRESSED BY A GENETIC COUNSELOR OR AN OPHTHALMOLOGIST WHO SPECIALIZES IN HEREDITARY RETINAL DEGENERATIONS. GENETIC COUNSELING IS PROVIDED AS PART OF THE DIAGNOSTIC EVALUATION IN MOST OF THE CENTERS RECEIVING SUPPORT FROM THE RP FOUNDATION FIGHTING BLINDNESS. A LISTING OF CLINICAL GENETIC SERVICE CENTERS IN YOUR STATE, PUBLISHED BY THE NATIONAL CLEARINGHOUSE FOR HUMAN GENETIC DISEASES, IS ALSO AVAILABLE THROUGH THE RP FOUNDATION FIGHTING BLINDNESS. IT SHOULD BE EMPHASIZED THAT GENETIC COUNSELING IS NON-DIRECTIVE AND NON-JUDGMENTAL.

23) <u>IF MY CHILD IS DIAGNOSED AS HAVING A RETINAL DEGENERATIVE CONDITION SUCH AS RP, WHEN AND WHAT SHOULD I TELL HIM</u>?

THERE IS NO HARD AND FAST RULE FOR EXPLAINING TO A CHILD THAT HE OR SHE HAS A RETINAL DEGENERATIVE CONDITION. CHILDREN HAVE VARYING NEEDS FOR INFORMATION DEPENDING ON THEIR AGE AND MATURITY. ALTHOUGH THEY ARE VERY PERCEPTIVE AND QUICKLY SENSE WHEN THERE IS

A PROBLEM, THEY MAY ONLY BE CAPABLE OF ABSORBING A LITTLE INFORMATION AT A TIME. ANSWER QUESTIONS AS FRANKLY AND POSITIVELY AS POSSIBLE, WITHOUT OFFERING MORE ANSWERS THAN YOUR CHILD HAS REQUESTED. HELP THE CHILD TO REALISTICALLY UNDERSTAND THAT SOME OF HIS OR HER LIMITATIONS MAY BE DUE TO THE VISUAL IMPAIRMENT, WITHOUT USING THIS CONDITION AS A CRUTCH OR EXCUSE FOR NOT REACHING A REASONABLE GOAL.

A PARENT OF A CHILD WITH A VISUAL IMPAIRMENT MAY FIND IT HELPFUL TO DISCUSS QUESTIONS AND CONCERNS WITH OTHER PARENTS IN A SIMILAR SITUATION. THE RP FOUNDATION FIGHTING BLINDNESS, THROUGH ITS AFFILIATES, OFFERS THIS OPPORTUNITY. PROFESSIONAL GUIDANCE MAY ALSO BE VERY HELPFUL.

24) <u>IS IT COMMON TO EXPERIENCE EMOTIONAL DISTRESS AFTER RECEIVING A DIAGNOSIS OF RP OR OTHER RETINAL DEGENERATIONS</u>?

YES. AFTER RECEIVING A DIAGNOSIS OF A RETINAL DEGENERATION SUCH AS RP, OR ANY SERIOUS DISEASE FOR THAT MATTER, IT IS NOT UNUSUAL TO EXPERIENCE FEAR AND CONFUSION. SOME PEOPLE ACCEPT THE SITUATION MORE QUICKLY THAN OTHERS. SOME EXPERIENCE A TEMPORARY PERIOD OF DEPRESSION BEFORE THEY CAN ACCEPT AND ADJUST TO THE CONDITION. IN ADDITION TO DEPRESSION, IT IS NOT UNCOMMON TO ALSO FEEL DENIAL, ANGER AND FRUSTRATION. SOMETIMES JUST KNOWING YOU ARE NOT ALONE MAY BE HELPFUL. IN THIS COUNTRY OVER 400,000 PEOPLE ARE AFFECTED BY RETINAL DEGENERATIONS. YOU MAY WANT TO CONTACT YOUR LOCAL RP AFFILIATE WHERE YOU WILL HAVE THE OPPORTUNITY TO MEET WITH OTHERS WHO HAVE SHARED SIMILAR EXPERIENCES.

25) <u>DOES A PROGRESSIVE LOSS OF VISION ALSO MEAN I WILL BECOME DEPENDENT</u>?

MANY AIDS, SERVICES AND TECHNIQUES ARE AVAILABLE WHICH PROVIDE A VISUALLY IMPAIRED PERSON WITH INCREASED MOBILITY AND INDEPENDENCE. SPECIAL LENSES, ORIENTATION AND MOBILITY TRAINING, AND ILLUMINATION ARE SEVERAL EXAMPLES. THE ABILITY TO FUNCTION INDEPENDENTLY CAN BE LEARNED JUST AS SPEAKING,WRITING AND WALKING ARE LEARNED. THE DEPARTMENT OF VOCATIONAL REHABILITATION, OR COMMISSION FOR THE BLIND OR VISUALLY IMPAIRED IN YOUR STATE OFFERS A NUMBER OF TRAINING

PROGRAMS TO ASSIST IN ADAPTING TO SUCH SITUATIONS AS TRAVEL, HOUSEKEEPING, EMPLOYMENT AND EDUCATION.

26) WHAT ARE LOW VISION AIDS?

LOW VISION AIDS HELP PEOPLE TO MAKE THE MAXIMUM USE OF THEIR REMAINING VISION. THE VISION AIDS MAY BE OPTICAL AIDS, SUCH AS CORNING AND NOIR GLASSES, THE FRESNEL PRISM, TELESCOPES, MICROSCOPES AND NIGHT VISION AIDS; NON-OPTICAL AIDS, SUCH AS THE WIDE ANGLE MOBILITY LIGHT, PAPER GUIDES, LARGE PRINT TYPEWRITERS AND ADJUSTABLE STANDS; AND ELECTRONIC AIDS SUCH AS APOLLO LASER AND VISUALTEK CLOSED-CIRCUIT T.V., READING MACHINES AND TALKING COMPUTERS. TO DETERMINE WHICH AIDS COULD BE HELPFUL FOR YOU, IT MAY BE NECESSARY TO OBTAIN A THOROUGH LOW VISION EVALUATION FROM A SPECIALIST IN THE FIELD OR A LOW VISION CLINIC.

27) WHAT ASSISTANCE DOES THE NIGHT VISION AID OFFER TO INDIVIDUALS WITH NIGHT BLINDNESS?

THE NIGHT VISION AID, DEVELOPED AND MANUFACTURED BY ITT, IS A HAND-HELD DEVICE THAT MAY BE HELPFUL TO SOME INDIVIDUALS AT A PARTICULAR STAGE IN THEIR RP WHEN THEY HAVE FUNCTIONAL DAYTIME VISION. THESE ARE EXPENSIVE ITEMS AND, IN SOME AREAS, MAY BE COVERED BY HEALTH INSURANCE OR STATE DEPARTMENTS OF REHABILITATION. ANYONE INTERESTED IN TESTING THE AID SHOULD CONTACT A NIGHT VISION AID SCREENING CENTER.

28) WHAT IS A NIGHT VISION AID SCREENING CENTER?

A NUMBER OF LOW VISION CENTERS AND HOSPITALS HAVE BEEN DESIGNATED AS SCREENING CENTERS FOR THE ITT NIGHT VISION AID. THEIR PURPOSE IS TO EVALUATE YOUR DAY VISION AND TO DETERMINE IF YOU ARE A CANDIDATE FOR THIS AID. FOR FURTHER INFORMATION ABOUT THE NIGHT VISION AID, INCLUDING A LISTING OF CURRENT SCREENING CENTERS IN THE UNITED STATES AND CANADA, CONTACT NIGHT VISION AID DISTRIBUTORS AT POST OFFICE BOX 207, RANDALLSTOWN, MARYLAND, 21133 OR CALL (301) - 655-1147.

29) <u>What about my career?</u>

Persons with retinal degenerative diseases can continue to lead productive lives and pursue desired career goals. By determining aids, training and other job modifications in the chosen field, potential problems can be identified and forestalled. Vocational counseling, offered through an educational institution, Department of Vocational Rehabilitation, or State Commission for the Blind can be most beneficial when planning or maintaining a career. Check your telephone directory for the number of your state or local agency.

30) <u>Can I donate my eyes to the Foundation for research?</u>

In 1980, the Foundation initiated a national Retina Donor Program to meet the acute, increasing need of our researchers to study retinal tissue from deceased persons affected by retinal degenerations or members of their families. A highly sophisticated retina donor notification and retrieval system has been developed so that eyes can be prepared and shipped to our researchers as soon as possible after death, in order for the specimen to be useful in biochemical research. Research efforts have already been greatly enhanced by the Retina Donor Program. This invaluable anatomical gift involves no cost to the donor's family or estate. Contact the RP Foundation Fighting Blindness for additional information and a Retina Donor Program consent form.

RP RESEARCH CENTERS

Receiving support from the RP Foundation Fighting Blindness

Berman-Gund Laboratory for the Study of Retinal Degenerations
Harvard Medical School
Massachusetts Eye and Ear Infirmary
243 Charles Street
Boston, Massachusetts 02114
617-523-7900 ext. 2624 or 2621

College of Physicians and Surgeons
Department of Ophthalmology
Columbia University
630 West 168th Street
New York, New York 10032
212-694-3468

Cullen Eye Institute
Baylor College of Medicine
6535 Fannin: NC#C403
Houston, Texas 77030
713-790-5964

Hermann Eye Center
Hermann Hospital
University of Texas Medical School
1203 Ross Sterling Avenue
Houston, Texas 77030
713-797-1777

Institute of Ophthalmology
University of London
Moorfields Eye Hospital
London, England

Jules Stein Institute
University of California
800 Westwood Plaza
Los Angeles, California 90024
213-825-6089

Medical College of Virginia
Department of Human Genetics
Virginia Commonwealth University
MCV Station
Richmond, Virginia 23298
804-786-9633

New York University Medical Center
School of Medicine
566 First Avenue
New York, New York 10016
212-340-7360

University of Illinois Eye and Ear Infirmary
1855 West Taylor Street
Chicago, Illinois 60612
312-996-8938

The Wilmer Ophthalmological Institute
Michael M. Wynn Center for the Study of Retinal Degenerations
Maumenee Building
Johns Hopkins University
600 N. Wolfe Street
Baltimore, Maryland 21205
301-995-7000

FOR MORE INFORMATION

CONTACT:	FOR ADDITIONAL INFORMATION CONCERNING:
RP FOUNDATION FIGHTING BLINDNESS 8331 MINDALE CIRCLE BALTIMORE, MARYLAND 21207 1-800-638-5682 1-301-655-1011 TDD: 1-301-655-1190 (FOR DEAF)	LOW VISION CENTERS AND AIDS, GENETIC COUNSELING, RP, USHER'S SYNDROME, MACULAR DEGENERATION, THE RP RETINA DONOR PROGRAM, AND CURRENT RESEARCH ON RETINAL DEGENERATIVE DISEASES.
NIGHT VISION AID DISTRIBUTORS, INC. PO BOX 207 RANDALLSTOWN, MARYLAND 21133 1-301-655-1147	NIGHT VISION AID INFORMATION AND LIST OF CURRENT SCREENING CENTERS IN THE UNITED STATES AND CANADA.
STATE COMMISSION FOR THE BLIND LOCAL LIONS CLUB	FINANCIAL ASSISTANCE.
STATE DEPARTMENT OF VOCATIONAL REHABILITATION STATE COMMISSION FOR THE BLIND	VOCATIONAL COUNSELING, REHABILITATION AND TRAINING; EMPLOYMENT; COUNSELING.
STATE DEPARTMENT OF EDUCATION	EDUCATIONAL PROGRAMS AND SERVICES OFFERED IN YOUR STATE.
SOCIAL SECURITY ADMINISTRATION	DISABILITY INSURANCE, SUPPLEMENTAL SECURITY INCOME (S.S.I.), MEDICARE AND MEDICAID.
VETERANS ADMINISTRATION	VETERAN'S BENEFITS.

CONT.

FOR MORE INFORMATION

CONTACT:	FOR ADDITIONAL INFORMATION CONCERNING:
INTERNAL REVENUE SERVICE STATE DEPARTMENT OF ASSESSMENTS AND TAXATION	TAX EXEMPTIONS (INCOME TAX, PROPERTY TAX AND DISABLED RENTERS' REBATES).
CENTERS AND SERVICES FOR DEAF-BLIND CHILDREN OFFICE OF SPECIAL EDUCATION 400 MARYLAND AVENUE S.W. DONOHUE BUILDING WASHINGTON, DC 20202 1-202-245-8749	PROGRAMS AND SERVICES FOR DEAF-BLIND CHILDREN.
HELEN KELLER NATIONAL CENTER FOR DEAF-BLIND ADULTS 111 MIDDLENECK ROAD SANDS POINT, NY 11090 1-516-944-8900	REHABILITATION, EVALUATION, COUNSELING AND OTHER SERVICES FOR DEAF-BLIND TEENS AND ADULTS.

NATIONAL SERVICE AND RESOURCE ORGANIZATIONS

NOTE: DUE TO SPACE LIMITATIONS, THE FOLLOWING IS A PARTIAL LISTING. IN ADDITION TO THE ORGANIZATIONS MENTIONED BELOW, THERE ARE NUMEROUS OTHER NATIONAL AND LOCAL ORGANIZATIONS, AGENCIES AND EDUCATIONAL INSTITUTIONS THAT PROVIDE SERVICES, ASSISTANCE, PRODUCTS, INFORMATION OR SPECIAL PROGRAMS FOR VISUALLY IMPAIRED INDIVIDUALS.

A. AMERICAN ASSOCIATION OF WORKERS FOR THE BLIND, INC. (AAWB)
206 NORTH WASHINGTON STREET
ALEXANDRIA, VA 22314
703-548-1884

A MEMBERSHIP ORGANIZATION OPEN TO PEOPLE WHO WORK WITH THE VISUALLY HANDICAPPED, AAWB PROVIDES EMPLOYMENT INFORMATION, REFERENCE INFORMATION CENTER, JOB EXCHANGE, CERTIFICATION OF REHABILITATION AND ORIENTATION/MOBILITY SPECIALISTS. PUBLISHES PROFESSIONAL PAPERS AND QUARTERLY NEWSLETTER.

B. AMERICAN COUNCIL OF THE BLIND, INC. (ACB)
1211 CONNECTICUT AVENUE N.W.
SUITE 506
WASHINGTON, DC 20036
202-833-1251 OR 1-800-424-8666

A NATIONAL MEMBERSHIP ORGANIZATION DEDICATED TO IMPROVING LIVING CONDITIONS OF THE BLIND AND VISUALLY IMPAIRED. PROVIDES LEGAL SERVICES AND PERIODIC TRAINING WORKSHOPS, CONDUCTS LEGISLATIVE ACTIVITIES, AND MAINTAINS 16 OCCUPATIONAL AND SPECIAL INTEREST AFFILIATES, AS WELL AS 51 STATE AFFILIATES. MONTHLY PUBLICATION: "THE BRAILLE FORUM".

C. AMERICAN FOUNDATION FOR THE BLIND (AFB)
15 WEST 16TH STREET
NEW YORK, NY 10011
212-620-2000

REGIONAL OFFICES:

ATLANTA, GA 404-525-2303
CHICAGO, ILL 312-269-0095
DALLAS, TX 214-630-8035
SAN FRANCISCO 415-392-4845

AFB PROVIDES INFORMATION AND SERVICES IN THE AREAS OF REHABILITATION, ORIENTATION AND MOBILITY, EMPLOYMENT, LOW VISION, LEGISLATIVE ISSUES, AGING, CHILDREN AND YOUTH, RADIO INFORMATION SERVICES, RECREATION, EDUCATION AND RESEARCH. MANY CATALOGS, INFORMATIONAL BROCHURES ARE FREE. ALSO PUBLISHES BOOKS, MONOGRAPHS AND PERIODICALS IN PRINT, RECORDING, AND BRAILLE; MANUFACTURES AND RECORDS TALKING BOOKS; DEVELOPS, MANUFACTURES AND SELLS AIDS AND APPLIANCES FOR THE BLIND AND VISUALLY IMPAIRED.

D. AMERICAN PRINTING HOUSE FOR THE BLIND
PO Box 6085
LOUISVILLE, KY 40206-0085
502-895-2405

PRODUCES EDUCATIONAL AIDS AND LITERATURE FOR THE VISUALLY IMPAIRED, BRAILLE AND TALKING BOOK EDITIONS OF SEVERAL MAGAZINES, BRAILLE BOOKS, MUSIC AND LARGE-TYPE TEXTS. MANUFACTURES SPECIAL EDUCATIONAL AIDS FOR BLIND AND VISUALLY IMPAIRED AND MAINTAINS A REFERENCE CATALOGUE SERVICE FOR STUDENTS.

E. ASSOCIATION OF RADIO READING SERVICES (AARS)
c/o AUDIO READER PROGRAM
UNIVERSITY OF KANSAS
PO BOX 847
1150 W. 11TH STREET
LAWRENCE, KANSAS 66044
913-864-4600

OVER 100 SERVICES IN THE UNITED STATES, AVAILABLE IN MOST STATES, PROVIDES ACCESS PRINTED MATERIAL FOR VISUALLY IMPAIRED ON CLOSED CIRCUIT RADIO. DAILY PAPERS, MAGAZINES, BOOKS AND LOCAL INFORMATION PROVIDED; ALSO TALK SHOWS AND PROGRAMS OF CONSUMER INTEREST ARE PRESENTED BY TRAINED VOLUNTEERS.

F. BLINDED VETERANS ASSOCIATION
1735 DESALES STREET NW
WASHINGTON, DC 20036
202-347-4010

BLIND VETERANS ARE SERVICED BY SUCH PROGRAMS AS COUNSELING, VOCATIONAL TRAINING AND INFORMATION ON BENEFITS. MAINTAINS FIELD SERVICE PROGRAM FUNDED BY THE V.A., AND OUTREACH EMPLOYMENT PROGRAM. PUBLISHES BIMONTHLY NEWSLETTER.

G. COUNCIL OF CITIZENS WITH LOW VISION
22 HOWARD STREET
NEWTON, MA 02158

AN ADVOCACY MEMBERSHIP ORGANIZATION PROVIDING PUBLIC EDUCATION, PROMOTING RESEARCH AND DEVELOPMENT OF PROFESSIONAL TRAINING IN LOW VISION, AND ESTABLISHING OUTREACH PROGRAMS.

H. DIALOGUE PUBLICATIONS, INC.
3100 OAK PARK AVENUE
BERWYN, ILL 60402

PUBLISHES QUARTERLY MAGAZINE IN BRAILLE, LARGE-TYPE AND DISC PROVIDING NEWS ITEMS, FICTION AND ARTICLES OF SPECIAL INTEREST.

I. NATIONAL ASSOCIATION FOR PARENTS OF THE VISUALLY IMPAIRED (NAPVI)
3329 NORTHAVEN ROAD
DALLAS, TX 75229
214-358-1995

A NON-PROFIT MEMBERSHIP ORGANIZATION COMPRISED OF AGENCIES AND PARENTS DEDICATED TO PROVIDING SUPPORT TO FAMILIES WITH CHILDREN WHO HAVE VISUAL IMPAIRMENTS. DEVELOPS LOCAL AND STATE GROUPS AND WORKSHOPS. NATIONAL CLEARINGHOUSE FOR INFORMATION, REFERRAL AND EDUCATION.

J. NATIONAL ASSOCIATION FOR VISUALLY HANDICAPPED (NAVH)
305 EAST 24TH STREET
NEW YORK, NY 10010
212-889-3141

3201 BALBOA STREET
SAN FRANCISCO, CA 94121
414-221-3201

AN ASSOCIATION PROVIDING YOUTH AND ADULT SERVICES, LARGE PRINT PUBLISHING, LIBRARY SERVICES, VISUAL AID INFORMATION, PUBLIC AND PROFESSIONAL EDUCATION, AND SPECIAL SERVICES TO SENIOR CITIZENS. SERVES AS ADVOCATE FOR PARTIALLY SIGHTED, AND OFFERS DEMONSTRATION AND PILOT PROGRAMS FOR YOUTH IN SAN FRANCISCO, ADULT DISCUSSION AND COUNSELING PROGRAMS IN SAN FRANCISCO AND NEW YORK, AND A CAREER PLANNING/JOB SEEKING WORKSHOP IN NEW YORK.

K. NATIONAL FEDERATION OF THE BLIND (NFB)
1800 JOHNSON STREET
BALTIMORE, MD 21230
301-659-9314 800-638-7518 (JOB OPPORTUNITIES FOR THE BLIND)

A MEMBERSHIP ORGANIZATION WITH STATE AND LOCAL CHAPTERS PROVIDING INFORMATION CONCERNING RIGHTS OF THE BLIND, PROGRAM DEVELOPMENT, JOB OPPORTUNITIES FOR THE BLIND (AN EMPLOYMENT PLACEMENT AND TRAINING PROGRAM). PUBLISHES "THE BRAILLE MONITOR" MONTHLY AND OTHER PUBLICATIONS. ADVOCACY AND LEGAL REPRESENTATION ARE PROVIDED. LOCAL PROJECTS TO IMPROVE CONDITIONS FOR VISUALLY IMPAIRED ARE DEVELOPED.

L. NATIONAL LIBRARY SERVICE FOR THE BLIND AND PHYSICALLY HANDICAPPED
LIBRARY OF CONGRESS
1291 TAYLOR STREET NW
WASHINGTON, DC 20542
202-287-5100

HEADS A NATIONAL NETWORK OF 160 COOPERATING LIBRARIES HOUSING EXTENSIVE COLLECTIONS. LENDS BRAILLE, TALKING BOOKS, AND MAGAZINES; PUBLISHES REGULAR CATALOGUES IN LARGE PRINT, BRAILLE AND RECORDINGS; PROVIDES TALKING-BOOK MACHINES AND ACCESSORIES,

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M. NATIONAL SOCIETY TO PREVENT BLINDNESS
79 MADISON AVENUE
NEW YORK, NY 10016
212-684-3505

INFORMATION AND REFERRAL SERVICES PROVIDED ON SPECIFIC EYE DISORDERS; LITERATURE PUBLISHED AND PROVIDED AT NO CHARGE. COMMUNITY SCREENING AND TESTING PROGRAMS, PUBLIC AND PROFESSIONAL EDUCATION AND RESEARCH PROGRAMS. SUPPORTS EYE RESEARCH. PUBLISHES BROCHURES AND PAMPHLETS FOR THE PUBLIC AND PRODUCES FILMS. ALSO PUBLISHES SIGHTSAVING, A QUARTERLY FOR PROFESSIONALS.

N. RECORDING FOR THE BLIND, INC. (RFB)
215 EAST 58TH STREET
NEW YORK, NY 10022
212-751-0860

PROVIDES RECORDED EDUCATIONAL TEXTBOOKS TO VISUALLY, PHYSICALLY AND PERCEPTUALLY HANDICAPPED STUDENTS AT ALL GRADE LEVELS, AND PROFESSIONALS. 58,000 TITLES IN LIBRARY CATALOGUE, 5,000 SPECIALLY TRAINED VOLUNTEERS AND 28 RECORDING CENTERS. SERVICE FREE TO MEDICALLY CERTIFIED REGISTERED BORROWERS.

O. VISION FOUNDATION, INC.
2 MOUNT AUBURN STREET
WATERTOWN, MA 02172
617-926-4232
1-800-852-3029 (TOLL-FREE IN MASS.)

PROVIDES INFORMATION, REFERRAL AND FOLLOW UP, SELF-HELP GROUPS AND BUDDY SYSTEM; PUBLISHES COPING WITH SIGHT LOSS, A COMPREHENSIVE RESOURCE BOOK. DISTRIBUTES MATERIALS IN LARGE PRINT, BRAILLE AND RECORDINGS, AND PUBLISHES NEWSLETTER IN LARGE PRINT AND CASSETTE.

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(n.d.)

Date Due

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AMERICAN FOUNDATION FOR THE BLIND
15 WEST 16th STREET
NEW YORK, N.Y. 10011